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National Institute of Transplantation

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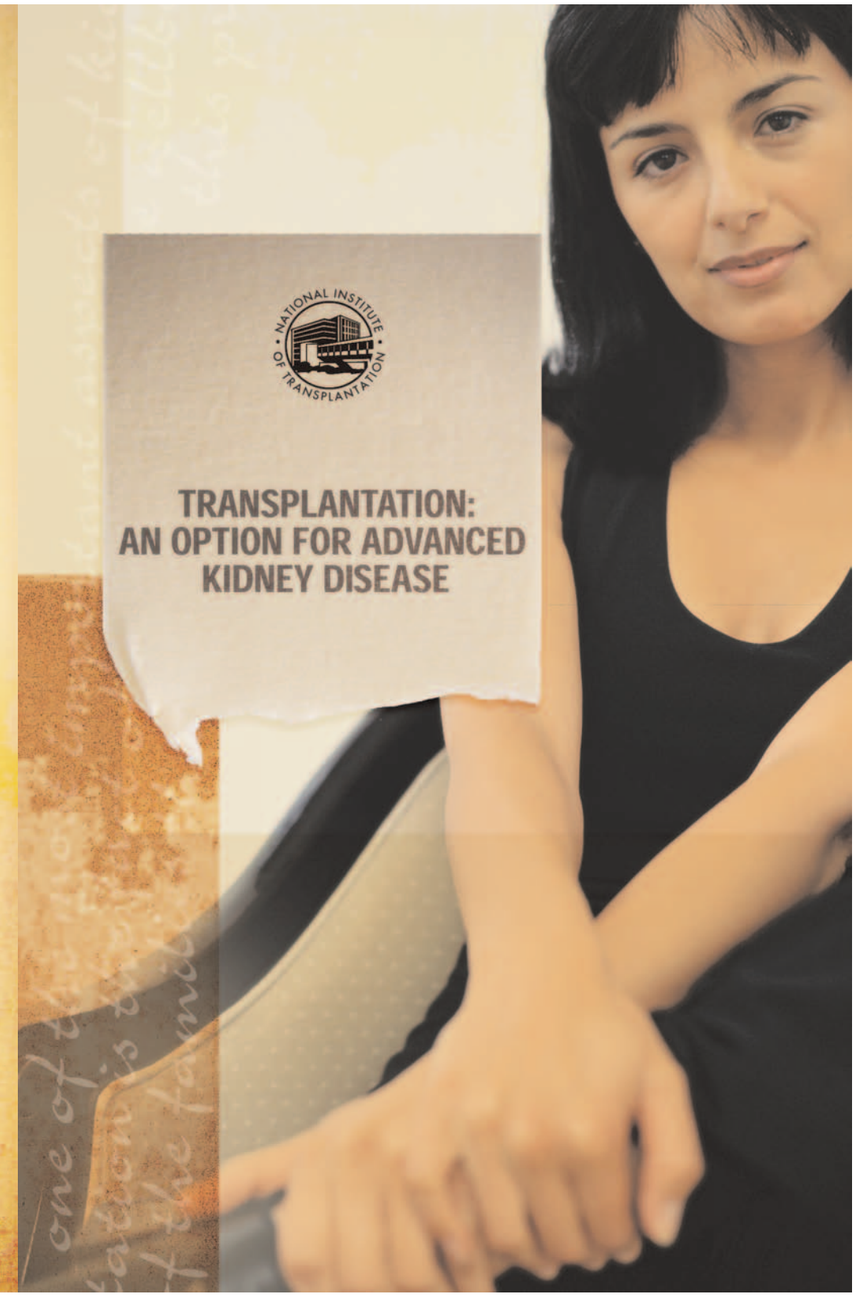
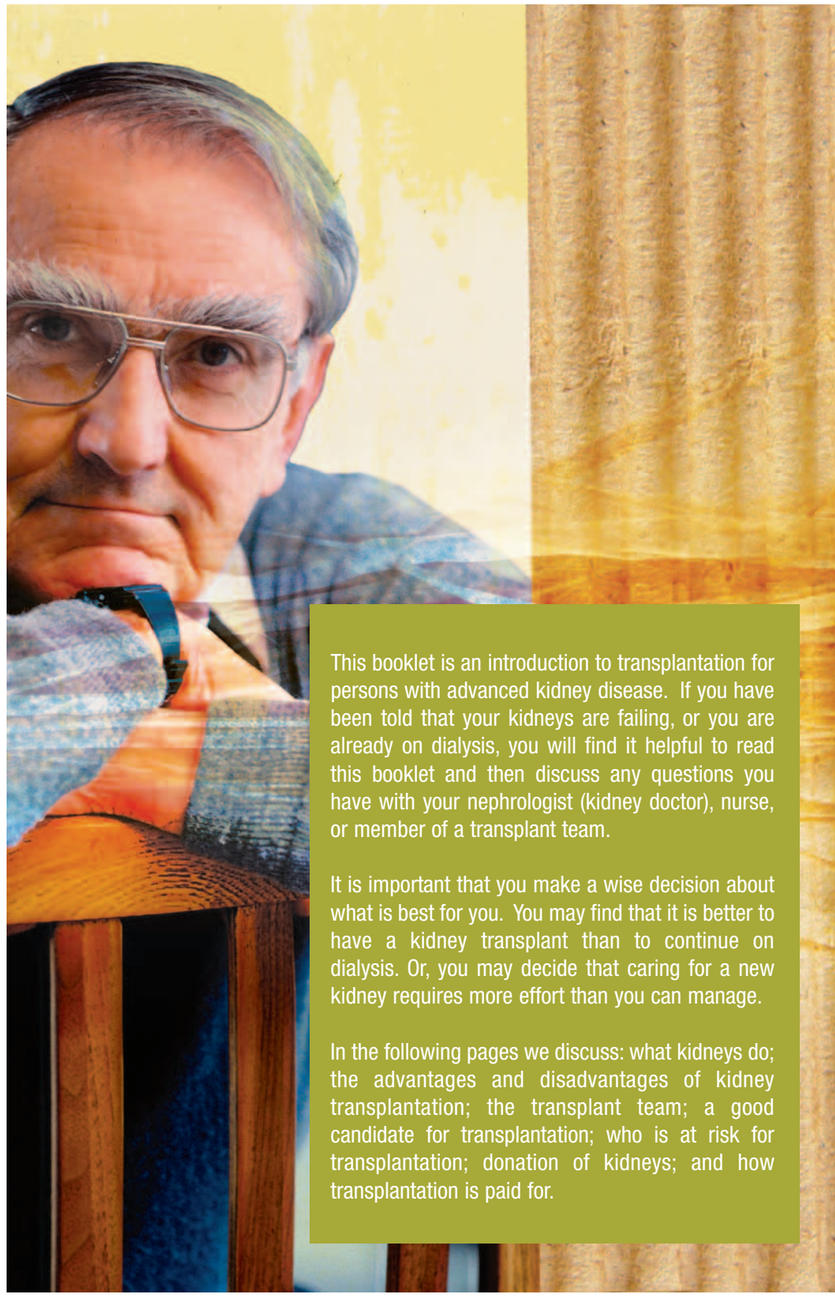
NATIONAL INSTITUTE OF TRANSPLANTATION





This booklet is an introduction to transplantation for persons with advanced kidney disease. If you have been told that your kidneys are failing, or you are already on dialysis, you will find it helpful to read this booklet and then discuss any questions you have with your nephrologist (kidney doctor), nurse, or member of a transplant team.

It is important that you make a wise decision about what is best for you. You may find that it is better to have a kidney transplant than to continue on dialysis. Or, you may decide that caring for a new kidney requires more effort than you can manage.

In the following pages we discuss: what kidneys do; the advantages and disadvantages of kidney transplantation; the transplant team; a good candidate for transplantation; who is at risk for transplantation; donation of kidneys; and how transplantation is paid for.

What Kidneys Do:

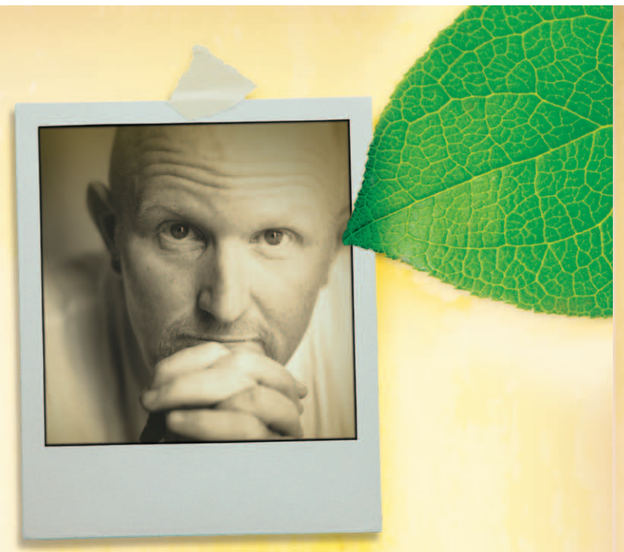
Healthy kidneys:

- Produce urine to help carry wastes out of the body.
- Balance the chemicals in your blood, such as calcium, sodium, and potassium. This process is necessary for your body to work properly.
- Produce hormones that regulate your blood pressure and help make red blood cells, which give you energy. If your kidneys are not working properly and produce too much or too little of these hormones, you may suffer from high blood pressure, anemia, fatigue, weakness or a general sense of being unwell.

Kidneys may become damaged and stop working because of diabetes, high blood pressure, inflammation of the kidney, or rarely exposure to harmful chemicals or medicines. Sometimes kidney failure occurs over a long period of time and sometimes it happens suddenly.

If the damage is great and you have what is known as end-stage renal disease (kidney failure), there are three options of treatment: hemodialysis, peritoneal dialysis, and transplantation.

End-stage renal disease is permanent. At best, dialysis may help you to cleanse about 15-20% of waste and unnecessary chemicals from your blood. Dialysis cannot produce the hormones you need. Only the transplantation of a healthy kidney may restore a person with end-stage renal disease to good health.



Kidney Transplantation

A kidney transplant is considered major surgery. It is an operation in which a healthy kidney is placed in the lower abdomen of a patient. In a two-three hour operation, the "new" healthy kidney is connected to your bladder and blood stream. Your damaged kidneys are usually not removed, unless there is an infection or problems controlling your blood pressure. After transplant surgery, most patients usually stay in the hospital for about four to seven days, but may be there longer if any problems develop.

Advantages of Transplantation

- Dialysis is unnecessary as long as the "new" or transplanted kidney is working.
- You will no longer have the strict dietary and fluid restrictions that you have on dialysis. For the most part, you are able to eat and drink what you want in moderation.
- You may lead a normal life of work or school, social activity, and exercise without having to schedule activities around dialysis.
- Your energy level is higher because the transplanted kidney is able to produce hormones that control blood pressure and help make new red blood cells. Dialysis is not able to produce these hormones.

Possible Complications & Disadvantages of Transplantation

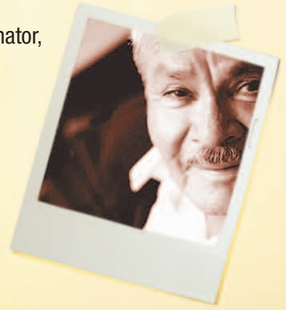
- Your body may reject the donor kidney. If this happens, you must return to dialysis. There is no way to predict how long a transplanted kidney will work.
- Daily medicine to fight your body's rejection of the new kidney is required for the rest of your life or the life of the transplanted kidney. Medications must be taken exactly as prescribed and you cannot miss a dose. These medications are strong and have side-effects.
- The medicines you must take each day may make it easier for you to catch infections.
- You may experience complications from surgery.
- New kidney disease may develop in the transplanted kidney or the old disease may redevelop.
- Risk of developing certain types of cancer is increased. This is a possible side-effect of long-term use of immunosuppressive medication.

The Transplant Team

Kidney transplantation requires many very skilled people to take care of you before, during, and after the surgery. You will have a team of people working their hardest to see that your operation is a success so that you can become well again and have a full and happy life.

The most important member of the transplant team is you. The success of your transplant operation depends on how well you take care of yourself and follow your doctors' instructions. About one-third of the transplants that fail do so because the patients did not follow the transplant team's instructions. To keep your new kidney working well, you need to understand the tremendous commitment in caring for your kidney. You need to be willing to talk with the transplant team immediately about any problems. You must follow their instructions. Your kidney transplant will require a lot of work from you.

The members of the transplant team are the surgeon, nephrologist, pre-transplant coordinator, hospital coordinator, post-transplant coordinator, social workers, dietician, pharmacist, support staff, and perhaps clergy, psychologists, and home healthcare workers.



It is very important that you work with each team member by telling them of any problems you may have.

Transplant Physician/Surgeon

If you decide that you would like to have a transplant, you will meet with a transplant surgeon and/or physician who will order a number of tests to evaluate your medical condition and see if you are fit and strong enough for surgery.

The surgeon who performs your transplant may not be the surgeon that you first met, especially if you are receiving a cadaveric transplant. Cadaveric transplants are not scheduled and you may be called at anytime of the day or night when a kidney becomes available.

Nephrologist

Your nephrologist, or kidney doctor, may have referred you to a transplant center and told you about your treatment options. You will continue to see your nephrologist while you are on dialysis and waiting for your transplant, and also after your transplant.

Pre-Transplant Coordinator

You will meet with a pre-transplant coordinator during your first visit to the transplant center. He/she is usually a registered nurse who is responsible for explaining transplantation to you and making sure that everything goes smoothly. The pre-transplant coordinator will begin looking for a new kidney for you by asking whether any relatives or close friends may be interested in donating one of their kidneys. If they are, then they must have some tests to see if your blood and theirs are similar. If no living friend or relative is found to have matching blood, the pre-transplant coordinator will place you on the waiting list.

Your pre-transplant coordinator is the person you should call if you have any questions. If necessary, he/she will refer you to another person with the information you need. Make sure you have your coordinator's name and phone number.

Hospital Transplant Coordinator

If you undergo a transplant, you will have a hospital transplant coordinator who will be responsible for coordinating all aspects of care during hospitalization. The main job of this coordinator is to educate you and your family on how to care for your transplanted kidney.

The coordinator will teach you about the medicines that help keep your new kidney working (they are called immunosuppressants). The coordinator will also explain possible side-effects of immunosuppressants, warning signs of infection and kidney rejection, and how you must care for your new kidney. You will be given a lot of information and it is very important that you understand everything you read and are told. Be sure to ask questions.

Your hospital coordinator is also responsible for planning your discharge from the hospital and scheduling follow-up appointments with your transplant surgeon and nephrologist. The coordinator will also help you schedule necessary lab work. Depending upon your needs, a home health service may also be ordered to ensure you do everything correctly when you return home.

Post-Transplant Coordinator

After your transplant, when you have returned home, you will be assigned a post-transplant coordinator. The post-transplant coordinator reviews all your lab test results and looks out for any signs of kidney rejection or infection. He/she will also be available to answer questions regarding your medicine.

If you have any questions, concerns, or problems, call your transplant coordinator immediately. There is a coordinator on duty 24 hours a day, seven days a week.

Dietician

During your hospital stay following your transplant surgery, you may meet with a dietician. The role of the dietician is to see that your nutritional needs are met and to educate you about the kind of diet you will be expected to follow after the transplant. He/she will also educate you about what you can do to not have so many side-effects from your medicine.

The dietician will help you establish and maintain a healthy diet and will work closely with your transplant surgeon to adjust the diet as necessary.

Social Worker (Pre- and Post-Transplant)

All potential transplant patients are required to have an interview with a social worker or mental healthcare professional to be sure that you have help available while you recover and to measure your ability to manage on your own, follow doctors' instructions, and take your medicine as ordered.

The social worker may help you: identify a care-giver; with your insurance; and with referrals to community agencies that can assist you further. After the social worker has completed his/her report, it will be sent to the transplant surgeon.

After your surgery, while you are still in the hospital, a social worker may meet with you and perhaps your family. The purpose of the meeting is to address any emotional or social concerns and help you deal with your discharge from the hospital.

Pre-Transplant Medical Evaluation

Before you can receive a transplant, it is necessary to undergo a series of medical tests. These tests are necessary to determine whether or not you are a good candidate for transplantation. Some may require that you see different medical specialists.

It is very important that you complete all medical requirements of the pre-transplant evaluation. You will not be placed on the national waiting list until all tests and evaluations are completed and sent to your transplant team. If you are determined to be a good candidate, more tests will be performed on the day of your transplant.

Your doctor is likely to request the following examinations:
- **Chest x-ray** to determine whether or not your lungs are healthy.
- **Cardiovascular tests (EKG, echocardiogram, angiogram, stress test)** to reveal the condition and strength of your heart.
- **Upper and lower G.I. (gastrointestinal) tests** to establish that your esophagus, intestines, and stomach are free of disease.
- **Blood tests** to indicate your blood and tissue type, blood chemistry, and to indicate the status of your body's immune system (ability to fight disease).
- **Kidney ultrasound** to create a picture of your kidneys.
- **Psychological evaluation** of your personal support system, resources, ability to manage on your own and follow directions of your medical team.

Additional tests may be ordered, depending on the status of your health, age, sex, and cause of kidney failure. These tests may include: abdominal ultrasound, prostate exam, mammogram, or Pap smear.

High-Risk Patients for Transplantation

There are several medical reasons that might make you a high risk for transplantation. However, even if you are a high risk you may still be eligible to receive a transplant.

High-risk patients include:
- Patients with diabetes
- Older patients with medical conditions that may reduce the likelihood that a new kidney will function
- History of cardiac disease or cardiac surgery, stroke, or a major infection
- Very young children
- Patients considering their second or third transplant
- Patients with a history of cancer

If you fall in this high-risk category, it is important for you to discuss in detail the advantages and disadvantages of transplantation with your surgeon.

Conditions That May Prevent Eligibility for Transplantation

You may have a medical condition that prevents you from being eligible for transplantation. Discuss with your nephrologist the possibility of transplantation. If you are interested in being evaluated for transplantation, contact a transplant center to schedule a consultation.

Conditions that might prevent you from undergoing transplantation include:
- An active infection
- Cancer
- Some autoimmune disorders - conditions wherein your body is allergic to its own immune system
- Severe medical conditions that affect your heart, lungs, stomach, or other organs
- Certain kidney diseases
- Being very overweight

If you have been told that you are not eligible for a transplant, ask why. Depending upon the circumstances, you may be considered a candidate at a later time. Only a transplant surgeon/physican will be able to provide you with this information.

Potential Kidney Donors

Once doctors have determined that you are a good candidate for a transplant, the search for a new kidney will begin. There are three categories of potential organ donors:

1) The **living, related donor** is a person who is related to you by blood; for example, mother, father, brother, sister, child, cousin, aunt or uncle.

2) The **living, unrelated donor** maybe a spouse or in-law, even a close friend. Any healthy person may donate a kidney and continue to live a full, healthy life.

3) A **cadaveric donor** is someone who, usually because of an accident, has been declared brain-dead and whose relatives have agreed to donate their loved one's kidney.

Establishing Compatibility

In order for a transplant to be successful, it is first necessary to establish that the donor's and the recipient's kidneys are compatible.

Important blood tests are conducted to establish compatibility:

- Blood type (A, B, AB, O)
- Panel Reactive Antibody
- Human leukocyte antigens (HLA)
- HLA Cross-matching

Human leukocyte antigens (HLA), the proteins located on the surface of kidney cells, are crucial in determining whether or not one person's tissues match another's and whether a transplant is likely to be successful. Everyone has at least six important antigens, and a perfect match occurs when the donor's and patient's six antigens are identical. Because brothers and sisters share the same parents, they represent the greatest possibility of a perfect match. Parents are also particularly good donor candidates since they automatically share at least three of the six antigens with each of their children.

Usually, a living donor is considered to be better than cadaveric and has a better success rate, regardless of matching.

Assessing the Potential Donor

Your transplant coordinator will ask if there are any family members or friends who would consider giving you one of their kidneys. If so, each potential kidney donor is required to undergo a comprehensive medical evaluation. The first step consists of blood tests to determine whether or not the potential donor and you are compatible. These tests include blood typing (A, AB, B, O) and HLA typing to establish which, if not all, of the six critical antigens you and the potential donor share. A cross-match is conducted to determine whether or not your body will accept the donor's kidney. If the cross-match is positive, then the donor is not compatible with you. If the cross-match is negative, further testing of the donor may occur.

Once a person has been determined to be a compatible donor, a complete medical history and physical examination will be performed, including lab tests and x-rays of kidneys. Women will also have a Pap smear and mammogram. Only individuals in very good health can donate. One must be free of diabetes, hypertension, obesity, kidney stones, and cancer. Both kidneys must be functioning properly.

Perhaps most important, a donor must be truly certain about wanting to be a donor. If a decision is made to donate, then before transplantation the donor will undergo an MRA. This is an advanced type of x-ray examination that will reveal the arteries and veins of the potential donor's kidneys.

In general, donating a kidney is a relatively safe procedure, but there are risks involved. After all, donating a kidney is major surgery. There is a possibility of allergy to anesthesia, infection, a temporarily collapsed lung, and even unforeseen complications that may require a longer-than-anticipated hospital stay.

Although a person requires only one functioning kidney for an otherwise healthy life, additional risks attached to such unpredictable events include development of protein leak in urine, high blood pressure, kidney disease, a tumor, and even such unlikely events as a gunshot wound, stabbing, or similar injury to the remaining kidney.

The Benefits of Donation from a Living Donor:

- Your waiting time is diminished. You will receive the organ while being in better health, rather than having to wait one to five years, which is the national average waiting time for a cadaveric kidney.
- The surgery will be done when you wish, rather than on an emergency basis, helping further to assure that you are in better health than after a long wait and possible declining health.

The Cadaveric Kidney

All cadaveric kidneys available for transplantation are registered immediately with the United Network for Organ Sharing (UNOS), a national program. Vital medical information on each waiting transplant candidate is entered in the UNOS computer data base in an effort to find a compatible donor kidney.

Although a perfect match is most desirable, often it is not possible. Cadaveric kidneys are assigned on a point system based on blood type and the number of antigens that will match those of the waiting patient, along with the length of time the patient has been waiting and medical condition. Age, gender, and race are not considered.

The average waiting time for a cadaveric transplant depends on your blood type. The approximate waiting period is:

AB - 1-2 years A - 3-4 years B - 5-7 years O - 3-5 years

The actual waiting period may be longer or shorter depending upon the availability of organs, antigen match and how reactive your immune system is.

Immunosuppression

As mentioned previously, medication is necessary for the survival of the transplanted kidney. A transplant recipient must take immunosuppressants (anti-rejection medicine) for as long as the transplanted kidney is functioning. The purpose of the medicine is to prevent your body from attacking or rejecting the new kidney. Your immune system cannot tell the difference between a new kidney and viruses or bacteria that might attempt to invade your body. Your immune system wants to destroy any "foreign" substance.

The importance of these medications cannot be over-emphasized: your kidney will not work without them. These medications: may cause undesirable side-effects; are expensive and may not be covered by your medical plan; weaken your immune system and make it easier for you to catch other illnesses; and must be taken every day. Your physician will work with you to maintain a fine balance in your medication to prevent rejection and yet have minimal side-effects.

Rejection

Rejection occurs when your body's immune system attacks your new kidney. There are two types of rejection: acute and chronic. Acute rejection may occur as soon as five to seven days after the surgery. Medical treatment exists for acute rejection and about 90 percent of these episodes can be treated successfully if detected and treated quickly.

Chronic rejection may start any time after transplantation-weeks, months, or even years afterward. It differs from acute rejection in that it causes permanent damage to the new kidney. However, new treatments are being developed and appear promising.

Who Pays for Transplantation?

The answer to this question depends upon each individual situation; many factors are involved. For example, you may qualify for a federal program (Medicare), a state program (Medi-Cal), have private health insurance, or a combination. It is important to understand that you are responsible for any charges that are not covered.

It is strongly recommended that you contact your insurance carrier and inquire about kidney transplantation coverage. Ask about office visits, hospitalization, post-transplantation office visits, lab tests, and medication costs. It is important to find out what your plan pays for anti-rejection medication because it is very expensive and is crucial to the survival of your new kidney. Be sure to check with your insurance plan regularly because policies tend to change.

Medicare

Medicare has an End-Stage Renal Disease Program. For those who are eligible, Medicare covers a majority of the costs. Contrary to what many believe, the Medicare program is not based on age or financial status. Your social worker at the dialysis unit will apply for your Medicare coverage. However, you are responsible for all monthly or quarterly Medicare premium payments.

Medicare may be the primary payor depending upon your type of insurance.
If you have private health insurance, then Medicare may be secondary.

Private Insurance

Private health insurance coverage for kidney transplantation depends upon each individual's health insurance policy. If you are covered by a Healthcare Maintenance Organization (HMO), it requires a referral from a primary care physician who is also a member of the HMO.

Other private health insurance providers will have their own scale of allowed payments. You should speak with your insurance company representative to get all questions answered so that you will be fully prepared before your transplant surgery. Remember to ask about coverage for immunosuppressant medication.

While Waiting for a Transplant

While you are waiting for a kidney, you may experience anxiety, stress and/or depression. This may be a difficult time for you both physically and emotionally. However, there are steps you can take to lessen your anxiety and/or depression.

- Learn as much as possible about the kidney transplantation process. Read patient education materials, talk with your transplant team and nephrologist. Talk to transplant recipients about their experiences.
- Attend a support group of persons in the same situation as you. Your transplant team can help you find a group.
- Maintain your daily activities. Stay busy.
- Exercise. Take walks or do something physical that you enjoy. This can help lift depression. However, talk to your physician prior to starting an exercise program to make sure that your program is appropriate for your current health status.
- Maintain a healthy diet and weight as recommended by your physician.
- Do something you enjoy every day. For example, read, call a friend, visit someone, etc.
- Get counseling, especially if your feelings of anxiety or depression have not improved and/or you are having a difficult time getting yourself to do things.
- Call your transplant team and inform them of any of the following changes: address, phone numbers, dialysis unit, insurance, nephrologist, and health status.

Making Your Decision

We hope this booklet has provided you with basic information about kidney transplantation. If you are interested in pursuing the option of transplantation, consult a transplant team. Your nephrologist or dialysis unit can help you find a transplant center. Ask the transplant team about the advantages and disadvantages of transplantation, especially in regard to your medical condition. Discuss immunosuppression and caring for your transplanted kidney before you decide that transplantation is the best option for you. Ask questions about all your concerns. Talk to transplant recipients about their experiences. If available, attend a support group for transplant recipients.

At the same time, talk with your nephrologist about the advantages and disadvantages of dialysis. Talk to patients who have been on dialysis for a long time. Be sure to discuss with your doctors before making any changes regarding your health, especially regarding medications, herbs and exercise program.

Your doctors will provide you with information about medical treatment; however, after you find out as much as you can about your treatment options for advanced kidney disease you will know what is best for you.

For further information about the kidney transplant process, please contact:
National Institute of Transplantation at 213-413-2779.